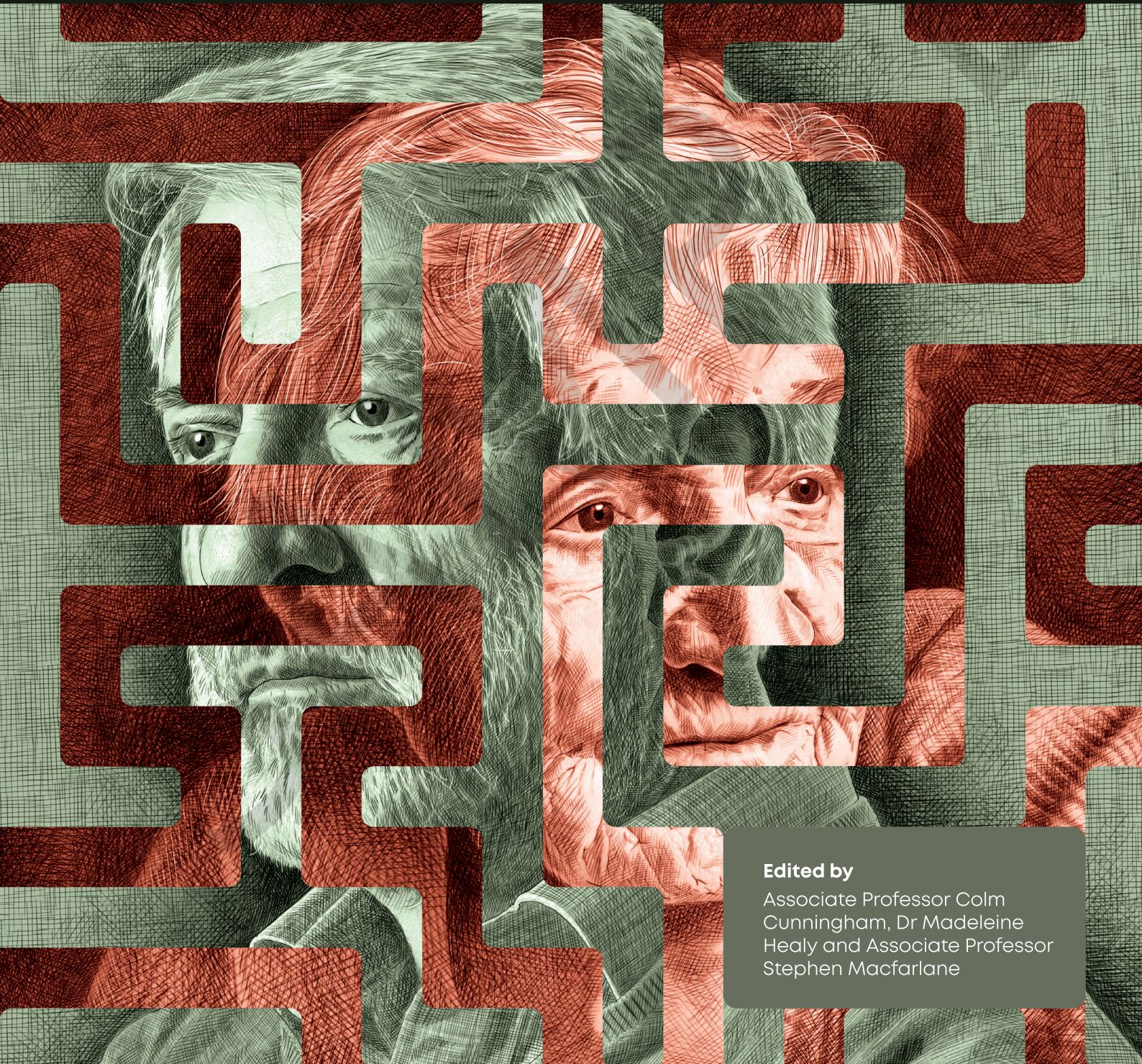


BPSD
Textbook

Addressing behaviours and
psychological symptoms of

Dementia



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Full text for sale at: Hammondcare.com.au/Shop

Published by HammondCare 2022

Sydney, Australia
publishing@hammond.com.au
www.hammondcare.com.au
ISBN 978-0-6486789-7-7
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Cover design: Fuller Studio

Internal design and typesetting: Eggplant Communications (Kerry Cooke)

Printing: Ligare Book Printers Australia



A catalogue record for this book is available from the National Library of Australia

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The editors and publisher welcome feedback on this book and the topic of psychosocial interventions for complex dementia care and support. Please contact us at publishing@hammond.com.au

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Foreword

Craig Ritchie

Since the turn of last century, neurodegenerative diseases have necessarily only been identified when people develop multiple symptoms associated with these brain diseases. These can be any multitude of combinations of a range of behavioural, cognitive or neuropsychiatric symptoms, with the individual often only presenting when these symptoms start to significantly affect day-to-day function.

As we grow into the 21st Century, there has been an accumulation of compelling and convincing scientific observations that the diseases that lead to dementia start to emerge at least in mid-life. We are learning that as they start, there may be numerous mechanisms interacting in a multitude of ways to lead to a dementia syndrome many decades later. Little by little, the complexities of these interactions are being unpicked and clinical services are being developed – sometimes even at a national level – to detect these diseases early and map out an individual's risk profile that may have underpinned the disease, and which could potentially be modified to change the disease's course as part of a personalised prevention plan. The pharmaceutical industry is looking at new methodologies for running trials in this 'at risk' population to complement personalised prevention with precision medicine.

Why this lengthy and upbeat opening about prevention?

Simply, we cannot allow ourselves as a community to be distracted by the 'brain health movement' at the expense of the ongoing, deep-seated and often poorly addressed needs of people living with dementia right now. The *BPSD Textbook* is a clarion call for those needs to be better noted, understood and managed.

It was my experience when working in Frankston, Australia in a psychogeriatric nursing home between 1997 and 2000, and then establishing a successful nursing home intervention programme in West London from 2010, that drove me towards prevention research and establishing brain health clinics in my native Scotland. But shifting my gaze to that prize was only possible because people like this book's editors and many contributing authors gave the same energy and passion to doing all we can to maintain and improve the wellbeing of people whose dementia wasn't prevented. It is likely of course that many millions of people globally will develop dementia over the next couple of decades while the prevention agenda takes hold.

This book is a scholarly, yet accessible source of knowledge for a range of professionals who play a critical role in the lives of people living with dementia. Foundations on the clinical syndromes and multifactorial aetiology of behavioural issues are followed by more specific outputs on symptoms, treatments, prevention and consequences of BPSD. It is a landmark achievement to bring so much contemporary knowledge into one place in such an easy-to-read book.

One day we will prevent dementia; one day it will be a rare condition at the very end stage of a disease process we are learning more and more about with every passing day. That learning will drive treatments and significant alteration of disease course. We must work in parallel though on gathering more resources, more energy and more inspiration for both prevention AND care. This book hits two out of the three things we need for better care of symptoms of BPSD by giving us energy and inspiration. Maybe that will lead to the third being achieved too. I hope so.

Professor Craig Ritchie is the Chair of the Psychiatry of Ageing at the University of Edinburgh in Scotland. His main academic interest is clinical trials and translational epidemiology that focus on mid-life and pre-clinical stages of neurodegenerative disease. He leads the PREVENT Dementia Programme as well as the EPAD (European Prevention of Alzheimer's Dementia) Project. He is the founding Director of Brain Health Scotland and chairs the Scottish Dementia Research Consortium. He developed his interest and passion for understanding, managing and preventing neurodegenerative disease when working between 1997 and 2000, with Professors David Ames, Ed Chiu and Colin Masters in Melbourne. He has published over 300 papers, book chapters and abstracts and has attained almost £100M of funding for his research to date.

Contents

<i>Foreword (C. Ritchie)</i>	<i>iv</i>
<i>Foreword (W. Eaton)</i>	<i>vi</i>
<i>Preface</i>	<i>viii</i>
<i>Introduction</i>	<i>x</i>
<i>How to use this book</i>	<i>xvi</i>
<i>The structure and functional areas of the brain</i>	<i>xx</i>
Part 1: Types of dementia	1
1. Alzheimer's disease	3
2. Vascular dementia	16
3. Dementia with Lewy bodies	24
4. Frontotemporal dementia	35
5. Parkinson's disease dementia and other syndromes	45
6. Huntington's disease	63
7. Other dementias	72
Part 2: Understanding changes in behaviour through holistic assessment	104
8. Lifestyle and biological factors	107
9. Psychological and psychiatric factors	138

10. Intellectual disability	164
11. Social factors	179
12. Environmental factors	212

Part 3: Specific behaviours commonly seen in dementia 226

13. Psychosis	229
14. Agitation and aggression	246
15. Depression	257
16. Anxiety	271
17. Apathy	285
18. Impulsivity	294
19. Walking or pacing	302
20. Vocalisations	312
21. Appetite and eating changes	322
22. Sleep disturbances	339
23. Distress during personal care	353
24. Wayfinding difficulties	370

Part 4: Common issues in dementia care 382

25. Delirium	385
26. Frailty	398
27. Falls	408
28. Palliative care and end-of-life care	418
29. Terminal agitation	434
30. Pain	448
31. Avoidance of restraint	465
32. Sexuality and intimacy	474

Part 5: Common medical issues and their effects on behaviours 488

33. Seizures	491
34. Pneumonia	501

35. Constipation	511
36. Dental care and oral health	521
37. Continence	535

Part 6: The role of medication in behaviour management **552**

38. Evidence for psychotropics	555
39. Cholinesterase inhibitors and memantine	569
40. Antipsychotics	577
41. Antidepressants	587
42. Mood stabilisers	599
43. Benzodiazepines	606
44. Emerging treatments for BPSD	615

Part 7: Supporting staff in implementing interventions **624**

45. Modifying the care environment	627
46. Tailoring approaches	655
47. Engagement: an opportunity	673
48. Monitoring success of interventions	689
49. Resilience for care staff: a practical approach	709

Part 8: Formulating interventions based on holistic assessment **720**

50. Formulating interventions based on holistic assessment	723
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<i>Acknowledgements</i>	756
<i>List of contributors</i>	758
<i>Figure, table and image credits</i>	763
<i>Bibliography</i>	765
<i>Useful resources</i>	789
<i>Index</i>	792
<i>About the editors</i>	803
<i>More from HammondCare</i>	805

INTRODUCTION

The starting point for providing better support for people experiencing behaviours and psychological symptoms of dementia, as covered in Part 1, is to appreciate the differentiators of the various forms of dementia. This may include causes, differences in trajectory, impact on diverse areas of the brain and common symptoms. Equally, it should not be forgotten that each person will have a unique experience of dementia, so knowing the person remains paramount.

“ It is difficult ... sometimes painful. But as we relate, as we love, as we struggle to hold onto one another in the midst of the storms of dementia, we know intuitively that there is something more; that the person before us is of worth, is valued, is a person. ”

– *John Swinton*

PART 1

Types of dementia

CONTENTS

01 Alzheimer's disease	3
02 Vascular dementia	16
03 Dementia with Lewy bodies	24
04 Frontotemporal dementia	35
05 Parkinson's dementia	45
06 Huntington's disease	63
07 Other dementias	72

Alzheimer's disease

Madeleine Healy and Stephen Macfarlane

In this chapter you will learn:

- causes, risk factors and genetic associations for Alzheimer's disease
- how Alzheimer's presents and is diagnosed
- what pathology underlies Alzheimer's disease
- how Alzheimer's is treated.

Alzheimer's disease is the most common form of dementia – affecting about 70 per cent of people living with dementia. Generally, Alzheimer's disease occurs sporadically in the population, although there are rare familial forms. It is also more common in people with Down syndrome.

In the rare familial forms people may develop Alzheimer's in their forties or fifties, but for most people onset occurs after 65 years of age and rates increase exponentially with age.

Alzheimer's is named after the German doctor Alois Alzheimer who first described the symptoms of Alzheimer's disease in 1907.

MULTIFACTORIAL CAUSES

The cause of Alzheimer's disease is a focus for ongoing research and is likely to be multifactorial. Pathologically, Alzheimer's disease is characterised by the presence of abnormal proteins – namely, amyloid plaques* and neurofibrillary tangles (composed of tau protein) – which are deposited in the brain.

To date, there is no specific diagnostic test for Alzheimer's disease. A likely diagnosis can be made on the basis of comprehensive clinical assessment (history and cognitive examination) in combination with brain imaging such as computed tomography* (CT) or magnetic resonance imaging* (MRI). Occasionally, nuclear medicine scans such as single-photon emission computed tomography* (SPECT) and positron emission tomography* (PET) can also be useful. The diagnosis can only be confirmed definitively at autopsy. See 'Making a diagnosis' later in this chapter for more detail.

RISK FACTORS

There are a range of characteristics, behaviours and activities that may increase the likelihood of developing Alzheimer's disease.

Age	The incidence of Alzheimer's disease increases with age and yet dementia is not inevitable with age. This may indicate that there are other disease processes, also associated with age, which predispose to Alzheimer's disease.
Education	Higher or continuing education is protective against progression of Alzheimer's disease. This is probably not because of education in itself; rather, it may be that education indicates more cognitive activity or 'exercise', which is protective. This creates a greater 'cognitive reserve', meaning the threshold for developing dementia is delayed and the person's ability to function is not affected until later.
Cerebrovascular disease	Vascular dementia and Alzheimer's disease often coexist as 'mixed dementia'. Cerebrovascular disease has been associated with more rapid progression and lowers the clinical threshold for dementia.
Hyper-cholesterolemia*	Observational data indicates that increased low-density lipoprotein (LDL) cholesterol increases the risk of Alzheimer's disease.

Hypertension	High blood pressure in midlife increases the risk of Alzheimer's disease and of dementia generally. This is probably due to an increased incidence of cerebrovascular disease in those with hypertension.
Obesity and metabolic syndrome	Obesity and type 2 diabetes increase the risk of development of Alzheimer's disease. There is ongoing research into the interaction between insulin and amyloid deposition.
Lifestyle and activity	People who are physically active have a lower risk of developing Alzheimer's disease. As with other lifestyle factors, this is probably due to a beneficial impact on cardiovascular health.
Medications	Recent data has raised the possibility that long-term use of strongly anticholinergic* medications (such as some antidepressants, bladder medications and antihistamines) may increase the development of Alzheimer's disease. The use of proton pump inhibitors (PPI), often prescribed for excess stomach acid, has also been raised as a possible link but the data is not clear.
Smoking	Smoking increases toxins, inflammation and oxidative stress in the brain as well as increasing vascular changes, and so may as much as double the risk of developing Alzheimer's disease. ¹

ALZHEIMER'S GENETIC BASIS

Despite identification of particular genetic associations, the genetic background to Alzheimer's disease is not well understood. Generally, genetic testing is not clinically useful, although families will often request it, particularly when there is a strong family history of younger onset dementia. This is mainly for future planning purposes as there is no disease-modifying agent that alters the course of the disease (there's no cure). As there are major implications of a positive test, genetic counselling is required before testing. Fortunately, genetics clinics usually offer this as part of testing for the major conditions currently identified as having genetic causes.

People with Down syndrome will inevitably develop Alzheimer's disease if they do not die of other causes. This is because the genetic abnormality involved in Down syndrome also gives people an extra copy of the gene that codes for amyloid precursor protein (*APP*), discussed overleaf.

¹ A. Ott et al., 'Smoking and Risk of Dementia and Alzheimer's Disease in a Population-based Cohort Study: The Rotterdam Study', *Lancet*, 351/9119 (1998), 1840–1843.

PART 2

Understanding changes in behaviour through holistic assessment

CONTENTS

08	Lifestyle and biological factors	107
09	Psychological and psychiatric factors	138
10	Intellectual disability	164
11	Social factors	179
12	Environmental factors	212

Lifestyle and biological factors

Madeleine Healy, Julie Christie, Agnes Houston, Elizabeth Stirling

In this chapter you will learn that:

- older age groups have proportionally higher use of alcohol and tobacco
- understanding and managing use or withdrawal in a care setting is vital
- older people and people with dementia experience a range of sensory challenges
- sensory changes may contribute to behavioural changes
- medical history is helpful in assessing biological factors
- particular types of dementia influence behavioural presentation.

The BPSD Textbook begins in 'Part 1' by including detailed definitions and descriptions of the different types of dementia. A key purpose is that providing an understanding of the various types of dementia and their specific presentations will promote awareness of particular symptoms of dementia and inform care and support, including in the context of BPSD.

Alongside this understanding, lifestyle and biological factors must be considered when developing a holistic assessment and seeking to understand and support changes in behaviour and other psychological symptoms.

ALCOHOL AND TOBACCO

Taking into consideration a person's current or previous pattern of consuming alcohol and tobacco (and, indeed, other prescription or illicit drugs) is an important part of supporting a person with dementia and understanding the cause of changed behaviours through holistic assessment.

Consumption of alcohol and tobacco may range from life-long abstainers to those with occasional past or present use through to heavy users who are strongly dependent.

Higher consumption in older age groups

People do not necessarily stop or reduce their consumption of alcohol or cigarettes due to growing older or receiving a diagnosis of dementia. In the UK, 23 per cent of men and 14 per cent of women consume alcoholic drinks on more than five days a week which is higher than any other age group.¹ In the USA, nearly 50 per cent of adults over 65 consume alcohol, and among these 14.5 per cent drink more than recommended.² In fact, alcohol, tobacco and other drug consumption can occur at a higher rate among people in their 50s, 60s and 70s when compared to the general population.³ For example, people in their 70s in Australia are the most likely to drink daily (12.6 per cent) followed by people in their 60s (9.6 per cent).⁴

Older adults are also significantly represented in tobacco statistics. In Australia, people in their 50s, 60s and 70s smoke the highest number of cigarettes per day (16.7, 16.5 and 15.5 cigarettes per day, respectively) and are also the most likely to smoke more than 20 cigarettes per day.⁵ The US Centers for Disease Control and Prevention reports that 8.2 per cent of adults over 65 years in the USA are current smokers.⁶

1 N. Zambon, 'Statistics on Alcohol: England', *House of Commons Library* (2021), <https://commonslibrary.parliament.uk/research-briefings/cbp-7626/>

2 S.R. Wilson et al., 'The Prevalence of Harmful and Hazardous Alcohol Consumption in Older US Adults: Data from the 2005–2008 National Health and Nutrition Examination Survey', *Journal of General Internal Medicine*, 29/2 (2014), 312–319.

3 Australian Institute of Health and Welfare (AIHW), 'Alcohol, Tobacco and Other Drugs in Australia – Older People', *Australian Institute of Health and Welfare* (2020), <https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/contents/priority-populations/older-people>, accessed 29 January 2021.

4 AIHW, 'Alcohol, Tobacco and Other Drugs in Australia – Older People'.

5 AIHW, 'Alcohol, Tobacco and Other Drugs in Australia – Older People'.

6 Centers for Disease Control and Prevention, 'Current Cigarette Smoking Among Adults in the United States', *Smoking & Tobacco Use* (10 December 2020), https://www.cdc.gov/tobacco/data_statistics/fact_sheets/adult_data/cig_smoking/index.htm, accessed 31 August 2021.

THE BASICS – WHAT YOU NEED TO KNOW

Alcohol and smoking

- Use of alcohol and tobacco is often higher in older age groups and so may be a significant factor in understanding the care needs and behaviours of a person with dementia.
- Withdrawal from alcohol, tobacco and other drugs, even when well managed, can lead to a range of symptoms that are similar to BPSD.

Sensory changes and challenges

- Sensory changes associated with ageing and dementia are important considerations in investigating the causes of behaviours in dementia.
- As dementia progresses, the person becomes more reliant on their senses to connect with the world.

Assessing the need for medical review

- Thorough assessment of medical history and current issues – including medications – is important in considering the biological contribution to changes in behaviour.
- In a care setting, basic physical assessment is helpful in identifying potential behavioural causes promptly so that they can be investigated and treated.

Acquired brain injury and dementia

- Acquired brain injuries are common and are categorised as traumatic and non-traumatic.
- Having a traumatic brain injury increases the risk of developing dementia.
- In older people, falls are a common cause of traumatic brain injury.
- Neurodegenerative disorders and stroke are causes of acquired brain injury that increase with age.

REVISION

1. Older people hardly ever drink or smoke. True or false?

2. Which condition in Huntington's disease may be misinterpreted as aggression?

- a. Memory loss
- b. Visual processing problems
- c. Chorea

3. Past medical problems may predispose a person to BPSD. True or false?

4. Acquired brain injury has symptoms that may also be associated with BPSD. Using this chapter, list as many symptoms as you can that could be confused with BPSD.

Psychological and psychiatric factors

With contributions by Elizabeth Stirling

In this chapter you will learn:

- understanding personality is an important part of holistic assessment
- awareness of preferences and routines may empower and validate
- being aware of past responses to stress can support better care
- the vital role of trauma history, particularly in relation to addressing PTSD
- how symptoms caused by mental illness overlap with BPSD
- how accurate history can help differentiate between BPSD symptoms and mental illness.

Four psychological factors that are key parts of holistic assessment when supporting a person with dementia experiencing BPSD are understanding personality, past responses to stress, history of trauma and mental health issues. Each factor will contribute to how a person approaches their life, their behavioural patterns and may be involved in changes in behaviour.

UNDERSTANDING PERSONALITY

CARE STORY – TATIANA

Tatiana is an 81-year-old woman who recently moved into an aged care home and lives with Alzheimer's disease. A tall and mobile woman, Tatiana has been referred for behavioural support for being verbally aggressive and leaving staff who are smaller than her feeling physically intimidated. After an initial period of seeming quite comfortable in the care home, she experiences distress during care, is refusing medication and finds it difficult to wait for assistance. According to Tatiana's family, her way of dealing with conflict or disagreement has always been to argue fiercely, then go away to think about the situation briefly before calmly coming to a resolution. They say Tatiana has always had a strong sense of independence and a robust dislike of bullies, doesn't like to be told what to do and is quick to take up the fight for the underdog. These characteristics are stable personality features and continue now Tatiana is in care, perhaps increased by reduced inhibition and living in a communal situation. A consultant helps develop a care plan that acknowledges that a quick temper is part of Tatiana's interpersonal communication style and staff are advised to not argue but validate by listening carefully, making eye contact, giving verbal affirmation and doing their best to help Tatiana feel that she has been heard. After this kind of behaviour, they are encouraged to help Tatiana find a quiet place to think and not be disturbed. Care activities with residents (e.g. taking them to the toilet) are minimised when Tatiana is present in case she misinterprets this as being coercive and feels she has to 'take control'. As these measures are increasingly implemented, Tatiana's verbal aggression decreases substantially and while she may still experience distress during care, this decreases when care staff are able to give her choice and to involve her in the process.

Personality refers to the characteristic ways that an individual thinks, feels and behaves. It includes moods, attitudes and opinions and is most clearly evident in interactions with other people. Although personality can change over a lifetime, core personality traits tend to remain relatively consistent during adulthood. Many factors influence personality, including genetics, family, culture, environment and society; the ongoing interactions between these factors continue to shape personality throughout a person's lifetime.

PART 6

The role of medication in behaviour management

CONTENTS

38	Evidence for psychotropics	555
39	Cholinesterase inhibitors and memantine	569
40	Antipsychotics	577
41	Antidepressants	587
42	Mood stabilisers	599
43	Benzodiazepines	606
44	Emerging treatments for BPSD	615

Cholinesterase inhibitors and memantine

Stephen Macfarlane

In this chapter you will learn:

- two classes of drug treatment that can support people with dementia
- that benefits are mild and temporary but aid cognition and functionality
- that side effects are mostly mild
- there is some evidence for BPSD improvement, including agitation.

Two classes of medication may be prescribed for a person with Alzheimer's disease and, less commonly, other forms of dementia with the aim of reducing or delaying some of the symptoms associated with the condition. Both drug classes aim to improve the action of neurotransmitters in the brain, but they also have some side effects.

In the context of BPSD, it is important to understand the effectiveness, limitations and possible behavioural and other side effects of these treatments to support holistic care.

CHOLINESTERASE INHIBITORS

Acetylcholine is a neurotransmitter (chemical messenger) that is important in brain function. Loss of cholinergic neurons is well demonstrated in many types of dementia and is associated with cognitive decline. Acetylcholine is broken down by

acetylcholinesterase; by blocking this enzyme, acetylcholine is not broken down and more is available for improved neurotransmission.

Timing and scope of benefit

Donepezil, galantamine and rivastigmine are all cholinesterase inhibitors and are approved or subsidised under various national schemes including the US Food and Drug Administration (FDA) and Pharmaceutical Benefits Scheme (PBS) for the treatment of Alzheimer's disease. Unfortunately, cholinesterase inhibitors only temporarily delay progression of dementia – they help damaged brain cells function better, but do nothing to modify the processes leading to this damage. Their benefit is mild and temporary, averaging somewhere between six months and two years. A two-point improvement on the MMSE* is considered to be a good response, as is an improvement in function, even if MMSE doesn't improve. There is currently no medication which is unequivocally disease-modifying, or curative for dementia.

There is evidence of benefit in several other types of dementia as well as Alzheimer's disease, although again the benefit of these is temporary. If not subsidised by a national scheme for this indication these may need to be paid for privately. However, a number of the agents available are now being produced by generic manufacturers, and the private cost is around A\$25 per month.

Summary of common drugs

Donepezil is a tablet and probably the most commonly prescribed cholinesterase inhibitor. Possible side effects include:

- diarrhoea and nausea
- aggravation of stomach ulcers and severe asthma
- loss of appetite
- bradycardia (slow heart rate)
- insomnia and vivid dreams
- muscle cramps.

The most serious of these is bradycardia, which can lead to syncope (fainting). Loss of appetite also needs to be closely considered in a frail older person, particularly if decreased appetite and weight loss are already issues.

Some side effects may be improved by switching to another cholinesterase inhibitor, or by making sure that donepezil is taken in the morning. Due to common problems with

PART 7

Supporting staff in implementing interventions

CONTENTS

45	Modifying the care environment	627
46	Tailoring approaches	655
47	Engagement: an opportunity	673
48	Monitoring success of interventions: behaviour, sleep, pain	689
49	Resilience for carers: a practical approach	709

Modifying the care environment

In this chapter you will learn:

- the elements and principles of a dementia-enabling environment
- how modifying the care environment can help to improve independence, reduce stress and manage risk
- the importance of appropriate lighting, noise levels, accessibility and familiarity in the care environment
- a range of modifications for each area of the care environment.

The primary aims of the care environment, as with all other aspects of care, are to reduce stress and distress and maximise function and autonomy for the person living with dementia, while maintaining safety and wellbeing. As discussed in Chapter 46, 'Tailoring approaches', the social model of disability holds that disability is a result of the interaction between people living with impairments and their environment – the implication being that disability can be reduced by adapting the environment to people's capabilities. Simple modifications to a home or residential care environment to meet the needs of people living with dementia allow them to participate more fully in everyday activities and experience the highest possible quality of life as they move through the stages of dementia.

This chapter deals primarily with adapting existing environments. The principles of designing a new care home that supports people living with dementia are discussed in detail in Chapter 12, 'Environmental factors'.

THE DEMENTIA-ENABLING CARE ENVIRONMENT

The care environment is a broad term but can be divided roughly into the built environment – encompassing the physical layout, building materials, fixtures, access points etc. – and fittings – encompassing furnishings, equipment, identification and security systems etc. Sometimes environmental considerations will extend across both aspects; appropriate lighting, for example, depends upon both the built environment (placement and size of windows, number and type of light fittings etc.) and equipment and furnishings (additional lighting such as lamps, placement of furniture to make effective use of light sources etc.).

Design and/or modification of the care setting to create an environment that is supportive to people with dementia can have significant positive outcomes for people with dementia. This type of environment has been described as a setting – i.e. built environment and facilities – that:

- promotes independence and supports wellbeing
- has familiar surroundings
- allows easy access and navigation (for more on wayfinding, see Chapter 24)
- supports meaningful engagement and participation in daily activities
- promotes safety, security and comfort.¹

The dementia-enabling environmental principles

There are various proposed guidelines in the literature for designing dementia-inclusive care environments. One widely used and evidence-based set of principles, developed in Australia, is the 10 Dementia Enabling Environment Principles.² These are:

1. Unobtrusively reduce risks
2. Provide a human scale
3. Allow people to see and be seen
4. Reduce unhelpful stimulation

1 Dementia Australia, 'How to Design Dementia-Friendly Care Environments', *Dementia Australia*, https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-Environment03_HowToDesign_english.pdf, accessed 20 July 2020.

2 Alzheimer's WA Dementia Enabling Environments, 'Dementia Enabling Environment Principles', *Dementia Enabling Environments*, <https://www.enablingenvironments.com.au/dementia-enabling-environment-principles.html>, accessed 20 July 2020.

Bedroom

- Beds should be visible on entry to the room and ideally accessible from both sides, however, individual needs and preferences should also be taken into account.
- Use tonal contrast to ensure the bed and bedding stand out against the flooring, and the covers from the bed. This can also provide an opportunity to personalise the décor, using preferred colours or even themed to a favourite sports team, to assist the person to recognise their bedroom.
- The bed should be visible from the toilet area (and vice versa) to assist with navigation, particularly at night.
- Height-adjustable beds can be set at the optimal height for the person or raised and lowered as needed. Beds should be at the right height for people to sit comfortably on the edge of the bed, with both feet flat on the floor. The standard seating height of a bed is 600 mm.
- Ensure that there is adequate night lighting, but that lighting is not disruptive to sleep.



Bedroom with toilet visible from bed at HammondCare's Caulfield Village (© HammondCare 2019)

Engagement: an opportunity

With contributions by John Swinton

In this chapter you will learn:

- the importance of engagement
- differences between engagement and activity
- the benefits of engagement
- modes of engagement and activities
- what to consider when planning, designing or evaluating activities and engagement opportunities.

Engagement – meaningful participation, whether alone or in company – is important for wellbeing at all stages of life, and its benefits extend to those living with dementia. Providing people living with dementia with opportunities for engagement suited to their capabilities can be challenging. However, the importance of such opportunities has been recognised in guidelines calling for health and aged care staff to provide support for ‘people with dementia and their carer(s) and families to participate in tailored activities that are meaningful and enjoyable’ in both community and residential care settings.¹

¹ Cognitive Decline Partnership Centre, *Clinical Practice Guidelines and Principles of Care for People with Dementia* (Sydney: NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, 2016).

ENGAGEMENT VS ACTIVITY

Not all activity qualifies as 'engagement'. Equally, not all engagement has to be activity-based. Particularly among people with dementia, some behaviours may reflect underlying boredom, confusion or even apathy rather than being an engaged behaviour – for example, the activity of watching television may not count as 'engagement' if the person watching has no interest in the program being shown. Engagement occurs where the person takes a participatory role (including making decisions, to the extent of their capability) in behaviours that are organised around an external stimulus and that either in themselves or through their objective create interest and offer a sense of meaning or purpose. But it is important to recognise that passive engagement can be just as important and meaningful to a person as actively participating in the activity.

This means that what qualifies as engagement will vary from person to person and will reflect each person's history, interests and capabilities. A one-size-fits-all approach will not succeed and activities organised around group participation may be engaging for some members of the group but not for others. The aim of engagement should be to help give a person a sense of contentment, fulfilment and/or purpose – it should not be merely to distract or occupy.

REFLECT

What are some activities commonly undertaken by people in care – home or residential – that are likely to foster genuine engagement? What are some that are more likely to be passive or require 'going through the motions'?

BENEFITS OF ENGAGEMENT

Engagement that is meaningful is important for wellbeing and offers many benefits for people living with dementia, including:

- a sense of purpose and goal-directedness
- increased self-esteem and awareness of capabilities
- the chance to utilise life skills and experience